Doctors, dying children and religious parents: dialogue or demonization?

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Abstract

A recent online article in the Journal of Medical Ethics, which received wide media coverage, raised the possibility that children are being 'subjected to torture' due to the 'fervent or fundamentalist views' of their parents. However, the quality of argument in that article was inadequate to sustain such a radical thesis. There was no engagement with the perspectives of different religious traditions about end-of-life care. Instead the authors invoked practices such as male infant circumcision which are wholly irrelevant to the end-of-life theme. There were serious failings in relation to core principles of social and epidemiological research practice: the study based its conclusion on a sample of only six cases and failed to consider even the more obvious confounding features. Rather than demonising the religious beliefs of parents there should be recognition of the need for mutual respect, dialogue based on an 'expert-expert relationship', and collaboration based on 'shared understanding'.

Five keywords: **withdrawal of treatment, children, parents, religion, dialogue**

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A recent article that appeared online in the *Journal of Medical Ethics*[1] has attracted considerable public media attention and raised some important issues. Two accompanying commentary articles[23] which identified serious concerns in relation to the article have been much less widely publicised. Bearing in mind the outcome of the *Lancet* Measles, Mumps and Rubella (MMR) article[4] – where the public media took up the substantive article and ignored the critique of the hypothesis which appeared in the same month in the Journal completely – we believe there is a professional and ethical obligation to comment where there is a real danger that the media reporting of an article could undermine public trust and cause serious, if unintended, harm.

In the article from Brierly, Linthicum and Petros, staff at one of the most prestigious Paediatric Intensive Care units in the UK have raised the possibility that children are being 'subjected to torture' due to the 'fervent or fundamentalist views' of their parents. Though professing to support 'shared involvement in decision-making', the authors characterise 'attempted dialogue' as hopeless where religion is involved, due to 'the parties not sharing the same language'. They therefore suggest the need to 'reconsider current ethical and legal structures' so that 'religion [is] legislated against in the best interest of the child'. In favour of their interpretation of medical intervention as 'torture', the authors cite Polly Toynbee's defence of assisted suicide,[5] whilst, in favour of their characterisation of religion, they cite Richard Dawkins' *The God Delusion*.[6] Given the choice of language and of references, it was entirely predictable that the content of this article would be disseminated widely in the national media.[7]

The relation of religion to end-of-life decisions in intensive care is an important topic meriting careful attention.[8] However, the quality of discussion in this article was consistently disappointing. Rather than engage with discussion of different religious traditions on end-of-life care, the authors invoke the practices of female genital mutilation and male infant circumcision, neither of which is relevant to end-of-life care. In particular, there is no real analogy between the withdrawal of life sustaining treatment, after which a child is expected to die, and male infant circumcision which, in the context of the developed world, is a safe and routine operation. Nor is circumcision exclusively based on religion. Whereas in the United Kingdom circumcision is practiced predominantly among Jews and Muslims, in other Western countries it is prevalent among the general population, as in the United States where at one time over 80% of male infants were circumcised[9] and where it is still the case that around one third undergo the procedure.[10] There have been some considered reflections on the ethics of male infant circumcision, especially in an American context,[11][12][13] but the cursory discussion presented by Brierly, Linthicum and Petros neither illuminates that issue nor the purported relevance of that issue to end-of-life care.

One might justify highlighting a sensitive issue such as the relationship of religion to withdrawal of treatment from dying children if the material is supported by careful adherence to core principles in social and epidemiological research practice. However, it is far from clear that this has been done in the article. In the first place the authors have not made the case that the phenomenon they identify represents a significant problem. It should be noted that in the great majority of cases (over 91%) agreement with parents was reached immediately, and in a further 6% it was reached by further discussion. In less than 3% of cases (6 children) was no resolution found and only one of these cases went to court. In identifying religion as the key feature of these six cases, the authors fail to examine other

possible contributory factors such as ethnicity, socio-economic status, educational status, and linguistic or cultural barriers – either within the whole cohort or in the problematic subgroup.

On the positive side, while the article is critical of 'protracted dialogue', such dialogue was shown to be successful in resolving two thirds of the problem cases. In relation to the very small number of remaining cases the authors refer to 'families from the African subcontinent', to 'churches with African… origins' and to the absence of 'religious community leaders available to attend meetings to help discuss or reconcile the differences'. These features immediately raise the possibility of other factors which are not explored in the paper, not least problems engaging with members of minority ethnic, linguistic, and immigrant communities.

Understood as a piece of epidemiological research, it is difficult to see how the paper would merit publication, given the sample size of only six unresolved cases, the lack of statistical analysis of the data set as a whole, and the absence of examination of other possible factors. The article was perhaps understood more as an ethical comment piece rather than a study, but in that case the use of data was both unnecessary and potentially misleading. This also raises the question of whether patient data that was not in the public realm - in regard to the religion of the parents of children who died in hospital - should have been made public without sufficient scientific justification.

It should also be noted that, while overtreatment is certainly one cause for concern, when disputes have come to court, it has not invariably been the case that judges have sided with the doctors. In at least one high profile case (that of Charlotte Wyatt), the judge considered that the doctors had not given sufficient weight to the interests of the child.[14] It is within not-

so-distant memory that doctors would routinely deprive neonates with Down's Syndrome of nutrition,[15] whereas today such a practice is recognised as 'unjustified and unethical.'[16] Hence one has to be very wary of reducing parental involvement or legal scrutiny and reverting to an approach which 'imposes the clinician's own values and fails to respect the child's and family's preferences'.[17]

When parents seek legal intervention to continue to treat, this is not necessarily due to a religious motivation (e.g. Child B).[18] The legal case by case evaluation cited in the commentary is preferable to withdrawing treatment as the default wherever the parents express religious faith. Furthermore, although these are always difficult to substantiate, there are recognised shifts in religious belief during illness and one may well imagine that these do occur amongst this group. These shifts could be towards deepening faith when confronted with mortality, as well as lessening faith when confronted with suffering. Such possible shifts are part of a reality where rigid guidelines are not helpful.

The underlying premise in this paper is that the universally accepted medical approach is 'secular' whereas the parents are 'religious', and that religious parents have less appreciation of the best interest of their child than do the secular medical professionals. This dichotomy is hard to justify philosophically; furthermore, there is good empirical evidence to show that many doctors do have strong religious beliefs.[19] In a religiously pluralistic society health care providers are as religiously pluralistic as patients and parents, and hence the picture given of simplistic confrontations between secular medicine and religious parents is very unhelpful. Notably Great Ormond Street Hospital and the associated Institute of Child Health are linked to University College London, a body that was founded broadly speaking on the philosophy of what has been called "procedural secularism" (i.e. that no one faith position

has a privileged position in the public arena and that free speech and conscience are protected) rather than on "programmatic secularism" (i.e. that no religion or faith position should have access to the public arena).[20]

One of our main concerns is that by publishing this article, the *Journal of Medical Ethics* has run a serious risk of endangering the trust between parents and doctors that is essential to the care of seriously ill children. The way that the article has been written is prejudicial to the perception of religion generally. Thus parents who are indeed religious could gain no confidence from it that they would in fact be included in treatment decisions. Furthermore, the elision of withdrawal of treatment decisions with assisted suicide gives the disastrous impression that reasonable and uncontroversial decisions to withdraw treatment as futile or unduly burdensome are in fact highly contentious, though covert, decisions in favour of euthanasia. If interest in this story were to be rekindled in the media or via the internet then parents might be reluctant to allow their children to be treated at that particular unit, or might approach conversations with doctors through a barrier of suspicion. Thus we regard the decision to publish this article in this form as irresponsible. If this danger has in fact been averted, this may owe more to the media distraction of the Olympics and Paralympics than to the foresight of the editors.

In our view both authors and journal editors should be commending to their readership the professional guidelines and legal precedents which encourage dialogue in this area. As embodied in the General Medical Council guidelines, the 'best interests' of the child include social, cultural and religious elements.[21] Rather than demonising the religious beliefs of parents there should be recognition of the need for mutual respect, a dialogue based on an 'expert-expert relationship',[22] and collaboration based on a 'shared understanding'.[23]

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